DRVD INVESTIGATION REPORT

AN INVESTIGATION INTO AN UNREPORTED INJURY, USE OF RESTRAINTS, AND G-TUBE FEEDING

A thirty-five-year-old patient at the Central Virginia Training Center sustained an injury to his nose on March 1, 1999. His parents did not learn of the injury until March 31, 1999 and filed a complaint with the DRVD concerning the injury. The complaint also raised issues concerning use of arm restraints on the patient and a G-tube feeding schedule that requires feedings at 4:00 a.m.

DRVD Case Number 99-0184

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I. INTRODUCTION

This report is a summary of the findings of the investigation conducted on behalf of the Department for Rights of Virginians with Disabilities (DRVD) into three complaints filed on behalf of PG, a thirty-five-year-old patient at the Central Virginia Training Center. These complaints concern an injury sustained by the patient to his nose on March 1, 1999; the arm restraint used to control certain behaviors exhibited by the patient; and the schedule for G-tube feeding that requires a feeding at 4:00 a.m.

The Department for Rights of Virginians with Disabilities authorized this investigation of alleged abuse and/or neglect of an individual with developmental disabilities pursuant to the Developmental Disabilities Assistance and Bill of Rights Act.

PG has resided at CVTC since 1982. He has been diagnosed as suffering from autism and severe mental retardation, and also has multiple medical problems. As the result of strokes suffered beginning in 1992, he is non-ambulatory, and spends much of the day in a "geri chair." In 1996, he was given a gastrostomy tube, and receives all of his nutrition through the tube. PG frequently engages in self-abusive behavior, primarily slapping himself in the face. When he exhibits this behavior, and less restrictive methods of controlling the behavior are not successful, his right wrist is tied to the arm of his chair with a terry cloth strip.

PG's parents follow his care closely and in that capacity, attended an annual meeting to discuss PG's treatment on March 31, 1999. At the meeting, the G's learned that PG had suffered a possible nose fracture over a month before. After learning about the fracture, Mr. G filed the complaint that is the subject of this investigation. He has expressed concern about possible abuse or neglect in connection with this incident. He also requested investigation of possible excessive use of restraints and a feeding schedule that, in his view, excessively interferes with PG's sleep. This investigation included the following:

- Review of PG's records from CVTC, including daily notes on his care, neuro-behavioral notes, restraint reports, doctor's orders, psychological evaluations, a Regional Support System Evaluation, material from the psychologist and social worker assigned to PG, and medical reports prepared by physicians both inside and outside the facility.
- Review of the initial incident report and a report prepared on all three complaints by Jon K. Oliver, Quality Systems Oversight Coordinator (now Director of Quality Assurance & Improvement).
- Review of pertinent laws, federal and state regulations, and CVTC policies.
- Interviews with Mr. and Mrs. G.
- Several interviews with Judy Dudley, CVTC Director, and Linda Harris, recently retired director of quality assurance.
- Numerous interviews with CVTC personnel, including PG's psychologist, social worker, physician, occupational therapist, nurses, including the nurse manager of skilled nursing, and certified nursing assistants.
- Interview with two outside consultants who have examined PG.
- Brief observations of PG.

II. BACKGROUND

A. Nature of the Facility

The Central Virginia Training Center is a training and long-term care facility for the mentally retarded. It has approximately 680 residents. The facility is licensed by the state Department of Health, which conducted a license review in October 1999. The facility is licensed through October 31, 2004. This includes the separate license the facility receives from the Department of Health for its skilled nursing unit, where PG currently resides.

When PG was first admitted to CVTC, he was placed in the Special Behavior Unit. This unit, which no longer exists, provided short-term, intensive treatment and training for mentally handicapped individuals with difficult behaviors, with the goal of returning those individuals to the community. While this goal was not appropriate for PG, CVTC determined that the SBU would be a good place to begin his rehabilitation from the deteriorated state he had reached prior to his admission at CVTC (see further details below).

B. History of PG's Treatment at Eastern State and the Central Virginia Training Center through 1991

PG is a thirty-five-year-old man who is diagnosed as autistic and severely mentally retarded. At the age of eight, his parents could no longer manage him at home due to his self-abusive and at times aggressive behavior, and he was admitted to Eastern State Hospital. When he was admitted to Eastern State, PG had developed a cataract in one eye due to self-abuse, and as a result is blind in that eye.

In the eleven years that PG resided at Eastern State, numerous forms of treatment and behavioral intervention were tried, without success. These included multiple medications, hand restraints, "extinction" (i.e. removal of teacher's attention), aversive electric shock, and "paired aversive stimuli" (i.e. snapping a rubber band on PG's hand whenever he hit himself). By the time PG arrived at CVTC in 1983, he was spending 22 to 24 hours per day in a mobile chair with four-point restraints, a covered donut around his neck and a fleece-type restraint on his upper body. It took three to five staff to feed, toilet, and bathe PG. He was exceedingly thin. His self-help skills were limited, and he had little opportunity to exercise.

PG was admitted to CVTC in February 1983. He was restrained as described above, and was admitted to the Special Behavior Unit (SBU). JO, who was unit manager of the SBU when PG arrived there told the investigator that PG arrived "drugged, naked, and strapped to a gurney." From that sadly reduced state, PG made considerable progress in the SBU. While mechanical restraints continued to be used, the staff also used several positive reinforcement techniques, including food rewards, praise, hugs, and holding hands. PG's self-help skills improved and his self-injurious behavior (SIB) decreased also. However, as has been true throughout his residence at CVTC, PG's SIB tended to be cyclical, and would increase and decrease for reasons that often could not be determined. Also, particular behavioral techniques tend to "wear out" on PG, or have the opposite effect than the one intended, so that new

strategies have to be developed frequently. Therefore, while PG made great progress on SBU, that progress was not linear.

PG's personality emerged while he was residing on the SBU. Staff who worked with him at that time, several of whom now work with him on the skilled nursing unit, recall him as mischievous, funny, and fond of women. He enjoyed running, both outside and on the unit, and sometimes leaped from chair to chair. When his father visited, he would bring PG a chocolate milkshake, and the two would then walk or run around the grounds. PG's speech improved during this time, and one of the staff memorably describes PG's voice as "low and passionate". PG also used hand signals to communicate. CVTC staff developed genuine affection for PG and he for them.

C. Deterioration in PG's Condition Beginning in 1992, Placement of G-Tube, and Efforts to Reduce Use of Restraints

In August of 1992, PG had a stroke. He had difficulty walking and using his left hand and leg. He was medicated for seizures beginning in July 1993. From this time until late 1995, his SIB was fairly well controlled, but his physical health continued to decline (see further discussion below). In February of 1994, it was determined that he could no longer function safely on the SBU, and he was transferred to another CVTC center, Rapidan Park.

PG had experienced difficulty in taking sufficient nutrition by mouth for years, and has also had a history of fevers of unknown origin. The fevers created a need for greater fluid intake, and PG was particularly reluctant to consume thin liquids. This caused dehydration, which became a serious medical problem. For example, in May 1995, PG was hospitalized for dehydration and fevers of unknown origin. The fevers continued, and SIB increased greatly over the level observed in 1993, 1994, and early 1995. As the result of intense SIB, PG injured the inside of his right cheek, and the lesion became infected. PG was hospitalized on September 15, 1995 due to the infection as well as dehydration. He continued to have health problems, and was hospitalized several more times over the ensuing months.

Beginning in September 1995, after the treatment for the infected lesion, PG was in restraints almost continuously for a year. He had become non-ambulatory by that time, likely as the result of additional strokes. The restraint consisted of tying his right arm to the arm of his geri chair. Due to the strokes, he had little use of his left arm. When released from the restraint, PG would become agitated, hit his jaw with great force, and grab and scratch staff.

By June of 1996, CVTC staff had become so concerned about PG's weight loss and inability/unwillingness to take liquids orally that a naso-gastric (NG) tube was placed. PG then gained weight and the problem with fevers diminished. However, the NG-tube caused PG considerable discomfort and irritated his nose and throat. Understandably, he became intent on removing the tube. As noted above, he was often in a poor state of health physically. All staff agree that PG becomes more agitated when he is in discomfort or ill. Therefore, it appears that the deterioration in PG's physical health, followed by the discomfort from the NG-tube, were the factors that resulted in almost constant use of restraints between the fall of 1995 and the fall of 1996.

Due to the problems with the NG-tube, CVTC proposed to the G's that surgery be performed in order to place a gastrostomy tube (G-tube). This proposal was based on the strong recommendation of a consultant from the Kluge Center at the University of Virginia. The G's requested a review by the Ethics Committee, which was performed in August of 1996. In May of that year, PG had been transferred to the skilled nursing unit, and was provided all of his personal care by nurses and certified nursing assistants. The Ethics Committee recommended that the surgery be performed, and also that continued efforts be made to have PG take food by mouth. The G's then agreed to placement of the G-tube, and the gastrostomy was performed on September 4, 1996.

After the G-tube was placed, PG's SIB and aggressive behavior improved considerably. In October of 1996, for example, he was in restraints for an average of four hours per day. However, at times the perceived need for restraints was much greater, ranging up to 23 hours per day.

After placement of the gastrostomy tube, the CVTC staff made a concerted effort to reduce the use of restraints and, more generally, improve PG's quality of life. PG's psychologist, SS was particularly instrumental in this effort, as were JO and other staff particularly familiar with PG. PG was placed in a quieter environment and the fluorescent lights were removed from his room. Several therapeutic techniques recommended for autistic persons have been implemented, including use of a "weighted blanket" for PG while he is in his lounge chair, and placing PG on a "mat table", which he apparently enjoys and at times has a calming effect. PG receives physical therapy, and several forms of occupational therapy have also been tried. Some of the therapy can be administered while he is on the mat table. SS has also obtained a harder mattress for PG's bed, which she believes is helpful. During the day, PG spends most of his time either in his geri-chair or on the mat table.

For approximately the past two years—varying responses were given by staff concerning this time period—PG has had with him a certified nursing assistant (CNA) at all times (for exceptions and additional details, see Sections IV (A) (4) and IV (C) below. The CNA is responsible for PG's personal care and monitors his behavior for SIB. Particular praise is given by all concerned to DC, a CNA who works with PG on first shift about four days per week. She talks to PG, gives him "wheelchair rides", takes him outside, and in general attempts to make PG's life as enjoyable as possible while at the same time monitoring him carefully for agitation and SIB. On his "calm" days, PG enjoys going outside, and has even gone on field trips outside CVTC, including to Monacan Park. DC, SS, and others have emphasized talking to PG during the last year, and PG has responded by beginning to laugh and verbalize more than he has in several years. His speech is difficult to understand, but at least a few phrases are intelligible.

Even with the many additional limitations that the strokes and other problems have placed on PG, his sense of humor remains intact—he has been observed pulling on staff with his toes and knocking over items left close to him. He also, on request, gives "eskimos" to staff—i.e. touches foreheads with them—as a sign of affection. While as discussed further below, PG is a very challenging client for several reasons, in particular his SIB, several staff

interviewed by the investigator expressed affection for him. Those who knew him in the SBU also express sadness at the deterioration in his condition due to the strokes and other illnesses.

D. Parental Involvement in PG's Care

The G's have always taken an active interest in PG's care at CVTC. Mr. G is legally PG's "authorized representative," and is the primary spokesperson for the family. Several of the staff interviewed during the investigation indicated that Mr. G has always wanted to know what kind of care and treatment PG was receiving, and pushed for the best care and treatment available. The G's have always asked to be kept informed of changes in PG's condition. In addition to speaking with CVTC staff by phone, Mr. G attends annual meetings concerning PG's care and treatment, and more recently has attended a number of the monthly meetings that are held concerning PG.

When PG was younger and able to be more active, the G's visited him every weekend. Currently, they visit about once a month. According to staff, the visits generally cannot last more than fifteen or twenty minutes at a time, because PG becomes agitated. In the staff's view, the agitation occurs because PG has difficulty in tolerating changes in his routine. In addition to the visits, the G's send PG gifts at birthday and Christmas, and cards on all appropriate occasions including birthdays and Valentine's Day. According to PG's social worker, PG enjoys "peeking" at the cards after they are read to him.

III. SUMMARY OF PG'S LEGAL RIGHTS

Mentally handicapped persons such as PG have a broad range of legal rights, and the facilities where they are confined have corresponding responsibilities, to assure that they receive safe and appropriate care. These rights and responsibilities derive from the United States Constitution as well as federal and state law, i.e. statutes and regulations. A summary of the rights and responsibilities most pertinent to this case provides a useful backdrop for the findings of the investigation.

A. Rights Derived from the United States Constitution

As a mentally handicapped individual confined in an institution, PG has a constitutionally protected right to adequate food, shelter, clothing, and medical care within the facility. He also has the right to a safe environment and reasonably non-restrictive conditions of confinement. Under the Constitution, he cannot be restrained unless professional judgment deems restraints necessary to assure his safety and/or the safety of the facility's staff. In this connection, the facility has the obligation to provide PG with such "training" as reasonably necessary to assure his safety and to facilitate his ability to function free from bodily restraints. See Youngberg v. Romeo, 457 U.S. 307 (1982).

B. Rights and Responsibilities Derived from Federal and State Law

Most of the residents' rights set forth below are also included in CVTC's own policies.

- PG has the right to be free from verbal, physical, and mental abuse and neglect.
- PG has the right to treatment under the least restrictive conditions feasible. The conditions in the facility must be consistent with an orderly, safe, and therapeutic environment. The right to treatment under the least restrictive conditions feasible includes the right to be free from unnecessary physical restraint. Restraint cannot be imposed for discipline or for staff convenience.
- The facility must notify PG's legal representative when there is an accident that results in injury and has the potential for requiring physician intervention, and of any significant change in PG's physical, mental, or psycho-social status. As discussed further below, the facility has its own notification policy, which requires the physician to notify the family of certain medical events, including fractures.
- There are several rights and responsibilities pertaining to "quality of life." These include provision of an ongoing program of activities designed to serve PG's physical, mental, and psycho-social well-being of each resident. They also require medically-related social services to attain or maintain the highest practicable physical, mental and psychosocial well-being. The facility must also maintain contact with PG's family in order to report on changes in health and current goals, and to encourage the family to participate in care planning.
- Federal and state law also establish rights and responsibilities pertaining to "quality of care" from a medical point of view. PG's medical care must be supervised by a physician. He must be provided with the care that will enable him to maintain the highest practicable level of physical, mental, and psychosocial health. This includes maintaining proper nutrition and also maximizing PG's use of language and related skills.

IV. CIRCUMSTANCES GIVING RISE TO THE THREE COMPLAINTS

A. Unreported Nose Injury

1. The Incident on March 1, 1999

On March 1, 1999 during first shift, MM was PG's one-on-one certified nursing assistant. FR and MP were the nurses on the unit. PG was suffering from nasal congestion and a cough, and nose spray had been prescribed. According to MM, PG became agitated and she called for help. MP put PG in restraints at 1:30 p.m. MM and MP initialed the restraint monitoring form, which indicates that when the restraints were applied, PG was agitated and hitting himself in the face. At 2:00 p.m., FR documented in the interdisciplinary notes that the bridge of PG's nose was swollen and slightly bruised. She consulted with KS, a nurse practitioner who was covering the patients normally assigned to Dr. P, PG's regular physician, who was out of the country. KS ordered an X-ray of the nose, and also cold compresses if PG would tolerate them. FR noted that PG was agitated and did not cooperate with the attempts to apply the cold compresses. PG was taken to X ray at 3:30 p.m. As of 4:25 p.m., he was still

agitated and in restraints. MF, a second shift nurse, was supervising PG's care on second shift. Second shift staff reported that they had been unsuccessful in applying cold compresses. KS ordered Tylenol to be administered. At 5:15 p.m., PG was calmer and the restraints were removed. The nurses were able to apply cold compresses while PG was sleeping. On March 2, KS examined PG again and noted that his nose was still swollen and showed "some deformity". She also noted that the nasal septum was deviated to the right. She described the injury to the nose as "self inflicted".

KS indicated to the investigator that she consulted with Dr. R, a CVTC physician every step of the way concerning appropriate treatment of PG's nose. Dr. R indicated that a nose fracture or other trauma to the nose should be treated symptomatically, as with the Tylenol and cold compresses. More aggressive treatment would be appropriate only if the patient were having difficulty breathing. KS continued to cover for PG's regular doctor until March 4, 1999, when Dr. D began to cover for Dr. P.

PG continued to receive Tylenol for nose pain until March 8th. The nursing staff and SS, the psychologist, believe that the nose caused PG considerable discomfort. The swelling initially increased, and then began to improve. The nurses' notes continue to remark on swelling until March 8th. Staff interviewed during the investigation described the injury in colloquial terms as a "big fat nose" and "right swollen". SS, PG's psychologist, and GS, the nurse manager of PG's unit, posted a notice in PG's room suggesting a heightened need for monitoring and restraint so that PG's nose would have a chance to heal. The G's have stated, and nurses and CNA's confirm, that PG's nose has never returned to its original shape; it continues to show some flattening across the bridge. This change is evident in "before and after" photos provided by the G's.

2. The X-Ray

The X-ray to PG's nose was read by two radiologists, and their reports conflict. The first radiologist indicated that the nasal bones were fractured, and that the age of the fracture was indeterminate, but likely old. He also stated that "[a] small defect in the anterior maxillary spine suggests old trauma." The second radiologist, who reviewed the X ray at the facility director's request, stated that the septum was not deviated—which was contrary to the observations of other professionals who have examined PG—and that there was no detectable nasal fracture.

PG had been examined by Dr. G, a private ENT specialist in Lynchburg, on August 7, 1998, due to bleeding from his nose. The purpose of that examination was to rule out nasal polyps. In this exam, Dr. G had noted that PG's septum was deviated to the left and that he showed "caudal deflection" to the right. PG also had significant excoriation and crusting on the right side, "probably secondary to self inflicted trauma as well as NG suctioning in that region". He prescribed Neosporin ointment. No X-ray was taken at that time, and no fracture or "crack" was mentioned. In a follow-up appointment on September 4, 1998, Dr. G stated that PG continued to have bleeding from his nose, and that he appeared to have had some self-inflicted trauma on the right side of his nose.

At the investigator's request, Dr. G examined PG again on August 7, 1999. In this exam he performed in August of 1999, Dr. G noted the deviated septum and caudal deflection that he had mentioned in his earlier report. He also noted that the "external nose" was deviated and angulated slightly on the dorsum, or bridge. In non-technical terms, this is the flattening or broadening of the bridge of PG's nose that has been observed by his parents and caretakers since the March 1 injury. Dr. G stated that this appeared to be due to nasal trauma "a number of years ago". (In fact, based on the reports of the CVTC staff interviewed, as well as "before and after" photos submitted by the G's, this appears to be due to the injury suffered in March.) He also stated that the X-ray taken in March when PG had the swollen nose showed a "crack" in the nasal bones, but that this was an old fracture.

In a consultation with the investigator on October 25, 1999, Dr. G acknowledged that he believes the nose fracture is old based on PG's history of self-abuse, rather than any characteristic of the X-ray itself. He stated that the significant deviation in PG's nasal septum and the caudal deflection, which he observed in 1998, were likely the result of an old impact injury. Overall, it is his opinion that PG's nose has been progressively injured by a combination of traumatic impact and the insertion of tubes, and that it is impossible to delineate old vs. new injuries.

3. PG's Parents Knowledge of the Incident and their Concerns

KS, the nurse practitioner who examined PG and ordered his treatment, acknowledges that she did not notify PG's family of the injury or attempt to do so. She believes that she consulted with FR, the first shift nurse, and was told that FR and the social worker, CB, would notify the family. However, FR does not recall this and indicated that she would not notify the family of something like a fracture because that is the physician's job. The social worker stated that the physician should report an event such as this, and that the physician may then ask her to follow up. She also stated that she did not find out that PG had undergone an X-ray until the annual meeting in March when the G's found out about the injury. Dr. P indicated that it "gets crazy" when the physicians and nurse practitioners have to cover for her on skilled nursing, but that this is not an excuse for failure to notify the G's. When she returned to the country in April, she assumed that the family had been notified right after the event.

On March 31, 1999, the G's came to CVTC in order to visit PG and to attend the facility's annual meeting concerning his case. The G's had not yet seen PG and had not been informed about the nose injury. During the meeting, Mr. G recalls PK, an occupational therapist, stating that the sensory program she was trying with PG had not been successful recently due to the problem with PG's nose. Mr. G then recalls asking, "what about his nose?" He then recalls that one of the nurses in attendance, FR, told him about the injury and that the X-ray had shown an old fracture. When the G's went to visit PG in his room, they could immediately see that his nose was misshapen in comparison to its pre-injury state.

The G's have several concerns about the injury to PG's nose. First and foremost, they are concerned that they were not informed of the injury or of the fact that an X-ray was taken. They are also concerned that although two reports have now stated that there is

an old fracture, or crack, in PG's nasal bones, there is no report in any earlier records about a fracture.

The G's are also concerned over whether it was in fact PG who inflicted the injury to his nose. The G's informed the investigator that to their knowledge, PG has never hit himself on the nose, and in any event does not hit himself hard enough to produce this type of injury. They also believe that PG is not very strong, and would be physically unable to inflict such an injury. And, even accepting the proposition that the injury was inflicted by PG himself, the G's question how such injury could possibly happen if the one-on-one aide was doing her job properly. Based on their observations of PG's behavior, they believe that it is not very difficult to hold PG's hand and keep him from hitting his face.

4. Nature of PG's SIB; History of Prior Injuries to his Nose

Prior to the X-ray performed on March 1, 1999, there is no indication in PG's records that his nose had actually been fractured. However, it is also true that PG has a history of SIB affecting his nose. There were several examples of this behavior in the month preceding the incident in March 1999. These include:

- 08/12/98 – nose markedly swollen in the morning; at 10:00 a.m. PG was hitting himself in the face 08/12/98 – nose still swollen on second shift.
- 09/03/98 – PG restrained at 8:50 a.m. for self-abuse; right side of nostril appears swollen
- 10/07/98 – while being bathed PG hit his nose, causing it to bleed and turn red
- 11/22/98 – PG hitting self in face, made right nostril bleed small amount
- 11/23/98 – right nostril bloody, both sides of face red There have also been similar incidents after March of 1999.

As these notes indicate, PG is capable of hitting himself with sufficient force to cause injury. Several staff described the loud sounds it makes when PG hits himself hard. DC noted that PG usually hits himself with the palm or heel of his hand, but that he also balls his fist and hits the front of his face.

Analysis of the one-on-one system used for PG provides insight on how injuries can occur even with one-on-one supervision. First, the system is designed not only to protect PG from injury, but also to allow him to be without restraints more often. To accomplish these dual purposes, the one-on-one aide is to observe PG's behavior closely, and to follow a protocol when he begins to hit himself in the face, which is his most common form of SIB. First, light pats or smacks to his chin or cheeks are considered to be simply for self-stimulation, and do not cause injury. Therefore, so long as the behavior consists of only this harmless form of behavior, the aide is to allow the behavior to continue. Second, if PG begins to self-abuse, the staff is to ask him to self-restrain. PG understands this request, and sometimes complies with it. However, DC, the most experienced one-on-one aide, reports that at times PG will put his hand

behind his back in order to self-restrain, and then pull it out very quickly and hit himself with force. DC reports that PG stretches his arm out before hitting, so that he can hit with more force. SS observes that PG often does not stop hitting once he has hurt himself; indeed, he appears to continue hitting and aims for "the hurt part".

In addition to asking PG to self-restrain, the CNA's employ other methods of controlling behavior. They try to re-direct PG's attention, for example to squeezing a koosh ball, holding hands, or to picture books. At times, PG will watch TV. Also, because the mat table has a calming affect on PG, the staff will sometimes place him on the mat table in an effort to stop the behavior. However, if PG has become very agitated before the mat table is tried, the staff has no choice but to restrain him. PG cannot be restrained on the mat table.

The CNA's also employ more direct physical methods of protecting PG. DC sometimes moves his hand up and down, but does not actually allow his hand to touch his face. She also holds his hand in order to soften the blow. However, DC also reports that PG is adept at blocking her hand if she tries to grab his arm. MM, the aide who was with PG when he was injured, indicates that she puts her own arm over the crook of PG's arm, so that he can land only a glancing blow. However, she also indicated that PG can shove her arm aside and come back around and hit himself again before she can catch him. She recalls that this happened on March 1, 1999, the day of the injury.

While PG has one-on-one aides during the daytime, these aides have duties other than sitting by PG's chair. For example, they must change PG's bed and do other tasks for PG in the room. Also, these aides need to take breaks, for example, in order to use the restroom. While they attempt to have another staff person remain with PG during their break, the unit is sometime short-staffed and common sense indicates that this is not always possible.

There is general agreement among the staff that PG functions better with staff who are familiar to him and who he seems to like. It is likely significant that DC was not with PG when the injury occurred. However, the aide on duty on March 1 works with PG on a semi-regular basis when DC is not on duty, so PG was at least somewhat familiar with her.

It should be noted that on 3rd shift, two of the staff interviewed stated that they did not believe that such an injury could happen on their shift, because they monitor PG carefully and put a particular priority on not allowing him to harm himself. However, the majority view on all shifts is that because PG's behavior patterns are unpredictable, and he can quickly become agitated enough to hit himself forcefully, an injury such as this one could occur on any shift, even when the staff is being attentive.

B. Feedings at 4:00 a.m.

1. Parents' Concerns about Feeding Schedule; Results of Change to Schedule at Parents' Request

The G's have long been concerned about their son's feeding schedule. Mr. G believes that the 4:00 a.m. feeding disturbs PG's rest and that as a result he misses

scheduled activities during the day because he is sleeping. Staff acknowledge that PG sometimes sleeps through activities during the day. The psychologist stated that if PG is sleeping when she wants to work with him, she wakes him up.

Until very recently, PG received tube feedings of eight ounces every four hours, i.e. 12 midnight, 4 a.m., 8 a.m., etc. With the exceptions discussed below, this has been his standard feeding schedule since June of 1998, when attempts to feed PG by mouth as much as possible were discontinued due to problems with aspiration and vomiting.

Even while PG was still taking some food by mouth, some liquid food was administered through the G-tube. Between September 1996, when the G-tube was placed, and May 1998, PG received either Suplena or Ensure Plus. Suplena is a higher calorie food than Ensure Plus, and was used more frequently. In May 1998, PG's physician noted that PG tolerated the Suplena better than he did the Ensure Plus, but had experienced diarrhea with both.

In July 1998, PG began to receive eight ounces of "Compleat modified" every four hours. This is a lower calorie food than either Suplena or Ensure Plus, but has ingredients that reduce the problem with diarrhea. In December of 1998, Dr. P ordered that two scoops of Promod, a protein supplement, be added to each feeding for three months.

At Mr. G's strong request, a new feeding schedule was adopted on April 21, 1999. The doctor ordered that PG receive eight ounces of "Ensure Plus," every three hours from 8:00 a.m. until 11:00 p.m. Three weeks before the change was made, Dr. P stated that if PG were fed every three hours and received the full six cans, this could cause vomiting.

On April 25, 1995, PG began vomiting large amounts of undigested food. He was admitted to the CVTC hospital, and given a diagnosis of bronchitis, caused by aspiration of food, and a paralytic ileus, which means that his small intestine had basically shut down. This was likely due either to the bronchitis or an electrolyte imbalance due to the vomiting. After this hospitalization, the CVTC physician sought and received Mr. G's permission to return to the previous feeding schedule. The food was changed back to Compleat modified. On July 7, 1999, Dr. P ordered eight ounces of Suplena to be given at 8:00 a.m. and 4:00 p.m., instead of the Compleat modified. One month later, the frequency of Suplena and Compleat modified was reversed. And, as discussed further below, at the end of October PG's physician agreed to discontinue the 4:00 a.m. feeding. She also replaced one of the Compleat feedings with Suplena, so that PG received Compleat only once per day.

2. Procedure for Tube Feeding

Only nurses, rather than CNA's, can administer feedings to PG. The procedure is as follows. At night, before PG is fed, his bed is raised to approximately 30 degrees. This is done in order to reduce the chance of aspiration of the food into PG's lungs. His T-shirt is then lifted, and the tube brought out. The nurse aspirates the tube with a syringe to make certain that PG's stomach is sufficiently empty. The food is then sent through the tube from its container. This is done by hand. The feeding process takes between five and ten minutes. PG's bed must remain elevated for up to an hour - - although a written order specifies

one hour, staff interviewed differed on the time -- to reduce the chance of reflux and aspiration. Most patients at CVTC cannot be fed in restraints, but because PG has to be restrained so often, this prohibition has been waived.

3. Nurses' Concerns' about 4:00 a.m. Feedings

There is general agreement among staff that the early morning hours have typically been difficult ones for PG. Several staff interviewed indicated that because PG is so often up at 4:00 a.m. anyway, the feeding makes virtually no difference in his rest or time in restraints. It is significant that the staff taking this position were not primary care staff, and generally do not work third shift.

The views of those on the "front lines" during third shift is different. Several nurses and CNA's noted that if PG is not already awake and agitated by 4:00 a.m., then he is likely to wake up and/or become agitated during the feeding process. He then has to be restrained. According to several staff members, PG is more likely to remain asleep or calm during the midnight feeding than during the 4:00 a.m. feeding. Several staff members observed that PG is less bothered by "personal care", such as changing his undergarment, than by the feeding. One nurse believes that lifting up the T-shirt to get the feeding tube is an agitating factor for PG; a CNA stated that lifting the blanket can have the same effect.

To determine whether these concerns about disturbing PG for the 4:00 a.m. feeding are valid, the investigator prepared a chart showing PG's time in restraints from January 1999 through June 1999. The chart indicates that PG was restrained for part of the day on 153 days during this time period. On 28 days, the restraint began in close proximity to the 4:00 a.m. feeding, including the post-feeding period when PG's bed would remain elevated. On 36 days, PG was already in restraints when it came time for the 4:00 a.m. feeding. It is impossible to determine whether feeding PG when he was already in restraints increased his agitation so that he had to be restrained longer than he otherwise would have been.

The nurses' other concern—likely their primary concern—is the danger of reflux and aspiration when a patient is fed in bed, even with the bed elevated. This danger is greater when PG is agitated. Reflux and aspiration create a significant risk of pneumonia. PG has had pneumonia at least five times from April 1998 through September 1999.

4. The Views of PG's CVTC Physician

Dr. P, PG's doctor, believes that round-the-clock feedings are necessary to keep PG's weight up and also to keep him properly hydrated. She stated that due to PG's difficulty with fevers and in maintaining the proper balance of sodium in his body, he needs more liquids than many CVTC patients do. She also noted that when evaluators come to the facility to review cases for compliance with federal requirements, they question weight loss, and it is therefore important to keep PG's weight up. In early April 1999, when Mr. G was requesting that the 4:00 a.m. feeding be discontinued, Dr. G noted that even with feedings every four hours during the previous month, he had lost two pounds.

According to PG's records, his "ideal weight" is between 115 and 125 pounds. It should be noted that although PG's weight has fluctuated over the past few months, his weight has not fallen below 115 pounds since April 1, 1997.

Since July 1997, Dr. P has included in her standing orders for PG's care the directive "do not get order to not feed at night due to weight loss." Dr. P does not clearly recall the original impetus for this order, but states that it was likely given because the nurses were requesting to hold that feeding when PG was agitated or because his temperature was up. The nurses would be required to obtain consent from the physician covering PG's care at that hour—who would often not be Dr. P—in order to hold a feeding.

Like Dr. P, the third-shift nurses were fuzzy on the reason that the "do not get" order was given. However, one nurse stated her recollection that in the past, nurses had attempted to "go around" Dr P to have the 4:00 a.m. feeding withheld if PG was having a bad night. A nurse also stated that unspecified members of PG's treatment team seemed to have the attitude that "You [on third shift] don't want to feed him." This nurse also stated that because these individuals are not there on third shift to observe what is going on, they do not understand third shift's concerns about feeding PG.

5. Outside Consultation with Dr. Fischer

The concerns expressed by the nurses have been echoed by a recent outside consultant, Dr. Leonard Fischer of Vienna, Virginia, who due to Mr. G's ongoing concern over the feeding schedule was brought in by CVTC to evaluate PG's feeding regime. The investigator had a telephone conference with Dr. Fischer on October 30, 1999. Dr. Fischer examined PG on October 8, 1999, and has conferred with staff by telephone on several occasions since then.

Dr. Fischer has worked with residents at the Northern Virginia Training Center, and based on his experience there he is generally opposed to nighttime feedings, for the same reasons identified above—i.e. disturbance to the residents' sleep and the risks the feedings pose of aspiration and reflux. The latter problem is compounded by the fact that at night, there are usually fewer staff available to monitor the resident's condition. He has observed these problems firsthand and therefore takes them very seriously.

However, Dr. Fischer also recognizes that PG's case differs from most because his stomach empties slowly, meaning that he can only be fed small amounts at a time. This makes it difficult to feed PG more frequently throughout the day and then hold feedings at night. Also, he has been told that PG does not have regular sleep patterns and in fact is often up at night, and also that he has one-on-one care at night. This means that the health risk is not as great, since PG is often seated rather than lying down when he is fed at night and also has staff to monitor his condition closely. It also means that the feeding itself does not disturb him as much as it would many other residents. As noted above, PG's records and the information provided by direct care staff indicates that while these problems are not as acute for PG as they would be for some residents, they are still significant.

Dr. Fischer has recommended, and CVTC has placed, a different type of tube for PG that should reduce the problem he has had with vomiting. Dr. Fischer had planned to recommend that the 4:00 a.m. feeding be deleted. However, shortly before Dr. Fischer's interview with the investigator, Dr. P had informed Dr. Fischer that she had decided to try this, so no formal recommendation had to be made.

Dr. Fischer also discussed using higher calorie foods for PG. There are liquid foods called Twocal and Magnacal that have two calories per gram. Suplena, which PG receives for some of his feedings, is close to that. Dr Fischer stated that if CVTC had to purchase food from a company different than its usual supplier in order to obtain the highest calorie food for PG, it would be worth it. He also agreed that if PG appears to need somewhat more sustenance than he receives without the 4:00 a.m. feeding, the midnight feeding would be the logical feeding to increase. He also stated that the bed needs to remain elevated for at least an hour after PG is fed.

C. Use of Restraints

1. The G's Concerns; Restraint Procedure

The third complaint raised by Mr. G is the facility's use of restraints for PG. The G's would like to see PG out of restraints as much as possible, so that he can receive more therapy, engage in more activities, and in general, have the highest possible quality of life. As noted above, the G's are skeptical of the need for frequent use of restraints, particularly given the one-on-one system of aides. It should be noted that Mr. G acknowledges that PG's time in restraints has averaged much lower over the past year than it has been in many prior years, but he is still concerned over the use of restraints.

As described above, PG is restrained by tying his right arm to the arm of his geri chair with a terry cloth band. He is restrained when he engages in SIB that is potentially harmful and cannot be controlled, and when he becomes aggressive toward staff attempting to care for him. Federal law prohibits restraining him for discipline or staff convenience.

Review of the daily notes on PG's care as well as many other documents pertaining to PG leaves no doubt that at times, PG must be restrained in order to keep him from hurting himself by hitting and scratching himself in the face. PG also attempts to bang his head against the wall or any other surface he can reach. The notes also describe numerous instances of PG's aggression toward staff, including biting, scratching, and hitting.

According to CVTC staff, PG is unique at the facility in terms of his need to be restrained on such a frequent basis. Accordingly, the procedure followed by the staff for restraining PG differs from the procedure set forth in the facility's Behavior Therapy Manual. The waiver of several procedural requirements is approved by the facility director and included in PG's behavior management plan, which in turn is approved by the local human rights committee.

When PG is restrained, the restraint must be approved by an authorized staff member (ASM). ASM's include registered and licensed practical nurses; they do not include CNA's. In order to be designated an ASM, all staff must successfully complete a training program.

After PG is placed in the restraint, his condition must be monitored and documented every fifteen minutes. This is done on a form designed for that purpose. He must be released for at least ten minutes after every one hour and fifty minutes in restraints. If he is still sufficiently agitated to pose a physical danger to himself or to staff, he is put back into restraints after the ten-minute break. DC, the CNA who works with PG most often, indicated that she generally allows PG at least 15 minutes out of restraints before deciding whether he needs to be restrained again.

For other CVTC clients, the psychologist must be notified every time the client is placed in restraints, and must approve continuation of restraints into the second hour. If restraints need to continue beyond that point, the physician must agree, and the psychologist and ASM must formulate a treatment plan for that particular situation. Also, for other clients the treatment team must meet after every application of restraints; for PG, the team meets monthly to discuss his case, including application of restraints.

PG averaged three hours per day in restraints in January 1999, four hours in February, six hours in March, three hours and twenty minutes in May, and two hours per day in June. During the six-month period charted by the investigator, the largest amount of time PG was in restraints on a particular day was 13 hours 15 minutes (June 26, 1999; restraints applied on three occasions during the day). On 33 days, he was not restrained at all.

2. Steps Taken by the Facility to Reduce Time in Restraints

As described in the background section above, after placement of the G-tube in September 1996, the CVTC made a concerted effort to reduce the use of restraints and to improve PG's level of functioning and quality of life. This effort is still ongoing, and at present seems to be spearheaded by SS, the psychologist, who JO states "has immersed herself in PG" and "is an expert on PG." The effort was strengthened and refined based on the recommendations of a special consultation report prepared in April 1998 by JO and others. The report reviewed PG's history and current situation, and made a series of recommendations to improve that situation.

The steps implemented by CVTC staff to lessen use of restraints and improve the quality of PG's life are as follows:

a. Use of a "one-on-one" aide for PG. Based on the recommendations in the special consultation report, this system was refined so that as few staff work with PG as possible. Another recommendation was that the staff who work with PG be self-nominated. These recommendations were based on the view that PG gets along better with staff familiar to him, and that certain staff have a better rapport with PG and therefore work with him more effectively. Due to staff turnover, staff shortages, and the hours of individual staff

members, it is not always possible to have CNA's working with PG who know him well. On third shift, four aides rotate by week in working with PG. As noted above, DC is the primary aide working with PG on first shift. On second shift, there have been more changes than on other shifts due to staff turnover. However, a particular CNA was recruited in September to work with PG on second shift, and this seems to be working well.

b. Placing PG on a firmly padded table, called a "mat table", for up to several hours per day. PG seems to enjoy being on the table and makes an effort to assist the staff in moving him to the table. He sometimes naps there. Some of the therapy that PG receives can be performed while he is on the table. When PG is becoming agitated, he will sometimes calm himself after being placed on the table. Staff must wait an hour after a feeding before placing PG on the table.

c. Use of a "weighted blanket" while PG is in his chair. This form of therapy is based on research by Temple Grandin, a well-known research scientist who is herself autistic. The blanket can be placed so that PG can use it to restrain his hands from SIB. If he pushes it off, it is not reapplied. DC states that "nine times out of ten" when she places the weighted blanket over PG, he leaves it there.

d. Placing PG in a quiet room with no fluorescent lights. The staff is careful to place only quiet clients in the room with PG. At times, PG has had two roommates; he presently has only one, who reportedly does not cause any noise or other disturbance bothersome to PG.

e. Use of a firmer mattress on PG's bed. When PG begins to exhibit SIB, the staff is supposed to attempt to control the SIB before restraints become necessary. The first step is usually to ask PG to self-restrain, which he does by putting his hand behind his back. He generally sleeps in a self-restrained position, i.e. hands behind his back. If PG will not self-restrain, the staff may try distractions such as the koosh ball, a picture book, talking or singing, or television. They may hold his hand or his arm so that he cannot hit himself, or so as to lessen the impact of the blow. At times, the CNA will summon a staff member known to be particularly effective at calming PG. If all else fails, the CNA notifies an ASM, usually one of the nurses on duty, and the restraint is applied. If PG is extremely agitated, it may take two or three staff to apply the restraint.

The above description represents the ideal situation. It is apparent from reviewing the daily "ID" notes and the neurobehavioral notes, which focus on application of restraints, that not every step is tried in every instance. There are a variety of reasons for this. First, if PG becomes very agitated quickly, there is not time to try to distract him from SIB. Some staff familiar with PG believe they have a "feel" for when PG is becoming too agitated for a lesser measure to work. Also, in interviewing CNA's, it was apparent that some of them have not had success with particular distraction and calming techniques, and therefore are less likely to use them.

Staff are unanimous that particular factors make PG more likely to need restraints. He reacts negatively to shift changes. He becomes agitated more frequently when he

is not feeling well, including when his fever has spiked. This pattern is clear in reviewing restraint records during times when PG was ill. And, as discussed above, some staff believe that the 4:00 a.m. feeding contributes to agitation.

As noted earlier, when PG taps himself lightly, this is considered harmless self-stimulation, and restraints are not to be applied. However, at least one CNA interviewed was not aware of this.

In addition to filling out a form every time PG is restrained, the nurse usually makes a "neurobehavioral note" indicating the behavior, the attempts made to redirect or convince PG to self-restrain, and whether the effort was successful. They also show instances where PG went successfully from restraints to the mat table, where he is not restrained. The investigator reviewed those notes for 1999 to determine approximately how often the staff used the mat table or the weighted blanket in an effort to calm PG.

This review is instructive. The notes show only one instance where the weighted blanket was tried. The mat table was used only a small proportion of the time in early 1999. For example, of 39 applications of restraints in January, the records show the mat table being tried only four times, and being successful once. In February, the notes mention one attempt to use the mat table, with PG placed in restraints 46 times. However, in July and September, the notes document 18 and 14 uses of the mat table, respectively, with a higher proportion of successful use.

3. Restraint Issues on Third Shift

From January 1999 through June 1999, PG was restrained for 658 hours. Of that time, 316 hours, or 48 percent of the total, were between 11:00 p.m. and 7: 00 a.m. As discussed in Section B above, on 28 occasions the restraint during this time period appears to have been related to the 4:00 a.m. feeding. Therefore, while the 4:00 feeding appears to be a significant factor in the time that PG is restrained on third shift, it is by no means the primary factor.

It should also be noted that when PG has been restrained for a significant period of time on third shift, he is often out of restraints shortly after first shift begins. Several staff indicated that once PG gets settled in on first shift, particularly when DC is on duty, he calms down and accepts bathing and other personal care.

Staff who have known PG for many years indicate that he has typically not slept well during the "wee hours" of the morning, and that his sleep patterns are in general unpredictable. While on some occasions he sleeps through these hours, it is common for him to wake up, and when he does he often becomes agitated.

The options for calming PG short of restraints were discussed with third shift staff during the investigation. The staff was unanimous that the mat table, the most effective "new" means of calming PG, has not worked on third shift. They indicated that they had tried using the mat table, but that when PG is agitated on third shift, he wants to be "up and

restrained", in the words of one person. The review of neurobehavioral notes for third shift shows one attempted use of the mat table in May, six in June, of which only one was successful, and one use in July. On that particular occasion, PG was able to move from restraints to the mat table. The records do not show any use of the mat table during third shift since July.

One of the nurses pointed out that on third shift, the staff has fewer options in distracting and redirecting PG—they cannot turn on the TV or read to him, for example. Third shift staff also made clear that the nurses' top priority in dealing with PG's agitation is to protect him from self-injury, and that if they perceive him to be at risk, they will restrain him.

The evidence also suggests that staffing patterns play a part in PG's being restrained on third shift. On third shift, there are supposed to be three aides working, and one of those is primarily with PG. However, when there are only two aides, which apparently happens fairly often, one aide cannot stay with PG all of the time because other patients need to be cared for throughout the night. One CNA indicated that they can hear the "smacking" sound PG makes when he hits his face and someone immediately goes in to check on him. When the unit is short-staffed, it is more likely that PG will become so agitated that he needs to be restrained before someone hears the "smacking" and goes into his room, so that lesser measures are not as likely to be effective. The same situation may also contribute to PG being left in restraints for a longer period of time. Also, on third shift a particular aide has not been assigned to work with PG; instead, the aides rotate.

V. FINDINGS AND CONCLUSIONS

A. Nose Injury

1. Occurrence of the Injury

PG's parents filed a complaint about the nose injury in part due to concern over abuse or neglect. As noted above, PG has the right to be free from abuse and neglect and also to a safe environment. He must also be provided the level of care that enables him to maintain the highest practicable level of physical well-being.

a. Nature of the injury

It is reasonably clear that PG's nose was broken at some point. Two out of three physicians who reviewed his records agree on this. The third physician's report is obviously inaccurate in stating that PG's septum is not deviated, and it is therefore less reliable than the other two opinions.

However, it is impossible to determine when PG's nose was broken. Although Dr. G felt that the fracture was likely old, this was based on history, not on the X-ray itself. The fracture could have occurred on March 1, 1999 or on a previous occasion. If it occurred previously, it was not diagnosed by means of X-ray. This does not necessarily mean neglect, however, so long as any swelling or other indications of trauma were treated

symptomatically. This is the way to treat a nose injury unless the patient has difficulty breathing or the airway needs to be opened wider for insertion of a tube or other instrument. Dr G indicated that when he sees patients with the symptoms exhibited by PG on March 1, he often does not perform an X-ray.

Whether PG's nose was broken on March 1 or not, all staff agree that the injury was serious enough to cause significant swelling and pain to PG. The medical staff was sufficiently concerned that an X-ray was taken. The injury was a possible fracture and was treated as such medically; it should also have been treated in that way for purposes of notifying the family (see discussion below).

b. The issue of abuse or neglect

There is no evidence that the injury to PG's nose was caused by abuse by an unidentified person. The information available—PG's history of forceful SIB, including to his nose, the documentation on March 1 that he had been hitting his face before he was restrained, and MM's recollection that he was very agitated and avoided her efforts to soften the blows, all indicate that PG caused the injury himself. While documents can be altered and recollections fabricated, the investigator finds those involved to be credible. And, the history of SIB, on its own, is compelling.

PG's parents are also concerned that FR seemed to have discovered the injury by happenstance, not because she had been told about it by MM or anyone else. This may be the case. However, it should also be noted that PG was placed in restraints at 1:30 p.m., and FR documented the swelling at 2: 00 p.m. Assuming that the injury occurred shortly before PG was placed in restraints, as is likely given the documentation, it may have taken the swelling a half hour or so to become obvious.

Finally, PG's parents are concerned that an injury of this significance could occur while PG has a one-on-one aide. This is a reasonable issue to raise. It may be that MM waited until things got out of hand before summoning help to place PG in restraints, and/or that PG began to hit his face while she was otherwise occupied. However, MM's account of the incident indicates that she was attempting to manage PG's behavior short of placing him in restraints, which is what she is supposed to do. And according to other staff, PG's behavior can escalate quickly. While MM may have misjudged this particular situation, there is insufficient basis for a finding of neglect.

c. Failure to inform PG's family

As noted above, federal regulations require that a patient's legal representative be notified of any injury that has the potential for physician intervention. Also, under CVTC's policy on event reporting, certain steps must be taken with respect to "serious" events, including fractures and permanently disfiguring injuries. These steps include immediate notice to the family via telephone by the physician. If the physician cannot reach the family before the end of his/her "tour of duty", another physician must continue the attempt to notify.

The Center Director must also be notified of the event, and she is then to notify the social worker, who must follow up the initial notification by telephone.

The facility's failure to notify the G's of the injury to PG's nose was a violation of both federal regulations and facility policy. The injury not only had the potential for physician intervention—a physician did intervene. And while the second reading of the X-ray may have created confusion about whether there was a fracture, and even the first reading stated that the fracture was of "indeterminate" age, this does not justify the failure to notify the family. The federal regulation alone required notification, and any doubt on application of the facility policy should have been resolved in favor of notification.

The facility director has expressed regret to the G's for failing to notify them of the injury, as has at least one staff member. However, it is not clear that the facility acknowledges that policy was violated. Nurse practitioner KS, who was covering for Dr. P was not aware until she was interviewed that the G's were not informed in a timely manner. This is unfortunate, as it was her responsibility to initiate the notification process. Even if her recollection is correct that the nurse told her that she and the social worker would notify the family, it was nonetheless her responsibility to initiate the process. Also, assuming that the facility director received the event report filled out FR after the accident, she should have notified the social worker and asked her to follow up with the family. This was apparently not done either, as the social worker indicates that she was unaware that PG's nose had been X-rayed until the annual meeting, when the G's first heard about it.

B. Feeding Schedule

Until the recent change, there were several concerns about the feeding schedule. If PG's rest was being disturbed unnecessarily, this was a problem in itself, and may also have increased the amount of time he spent in restraints at night and made him too sleepy to participate in daily activities. This would implicate PG's right to services designed to attain the highest practicable physical, mental, and psychosocial well-being as well as his right to live free from bodily restraint to the greatest extent feasible. The other concern is that the heightened danger of reflux and aspiration creates and unreasonable risk to PG's health.

As discussed in the sections on feeding in Part III B above, several staff on third shift have been concerned that the 4:00 a.m. feeding was an agitating factor for PG. Their concerns are borne out by the restraint records; the feedings appears to have been a significant factor, although not the primary one, in the use of nighttime restraints. These observations are in opposition to the "majority view" of staff at CVTC, primarily staff who are not involved in direct care and/or do not work on third shift, who believe that the "wee hours" of the morning are a difficult time for PG and that the feedings are not a factor in that longstanding problem.

There is some evidence that being awakened at night has an effect on PG's ability to engage in daily activities. However, the psychologist who frequently works with PG does not perceive this as a significant problem.

The concerns about disturbing PG and making him tired in the daytime would of course be overridden if the 4:00 a.m. feeding were necessary for health reasons. And in turn, these health concerns must be balanced against the risks created by feeding PG in bed. There is no doubt that Dr. P has worked carefully to find the right mix of liquid foods for PG. The combination of Compleat modified and Suplena that he currently receives seems to strike a balance between PG's need for calories and his tendency to develop diarrhea from the higher calorie foods. Dr. P also monitors PG's blood work carefully, including his sodium levels, and has worked to design a diet that meets those needs and also the necessary hydration level for PG.

However, until the recent change in PG's feeding schedule, it did not appear that all available options on PG's feeding schedule had been tried. When the 4:00 a.m. feeding was briefly eliminated in April of 1999 after Mr. G's numerous requests, Dr. P rearranged his schedule in a manner so drastic that the change was almost bound to fail. PG's stomach needs time to empty, as Dr. P has noted, and yet Dr. P ordered eight ounces to be fed every three hours. She predicted that this would cause vomiting, and it did. Dr. P also changed the food to Ensure Plus, which PG had tolerated very poorly in previous trials. The notes indicate that he tolerated this food the worst of any of three that he has had. After four days, PG was quite ill and had to go to the hospital.

The investigator also perceived that the direct care staff do not feel "heard" by Dr P with their concerns over disturbing PG or their concerns over the danger of reflux and aspiration. While not criticizing Dr. P, the nurse manager indicated that when PG was stable and at a good weight, she thought it would be worth trying to simply eliminate the 4:00 a.m. feeding but keep the rest of the schedule the same. Now that Dr. Fischer has done a consultation, this change has been made, and Dr. Fischer plans to continue to follow up and monitor the situation. Given this recent development, there is no need to make findings on the feeding issue. In Part V, there are several recommendations designed to assure that the new feeding regime will be given maximum opportunity to succeed.

C. Restraint Issues

PG has the right to treatment under the least restrictive conditions feasible, including freedom from unnecessary physical restraint. He cannot be restrained for convenience; he can only be restrained when, in the judgment of a professional, restraint is necessary to assure his safety and/or the safety of the facility's staff.

PG's parents acknowledge that PG is in restraints for much less time than he has been in the past. However, they believe that the one-on-one system should reduce the need for the arm restraint even more, and possibly eliminate it entirely. If true, this would justify a finding that PG's rights are not being respected to the maximum extent possible.

However, as discussed in detail elsewhere in the report, it is not always possible to redirect PG's attention, convince him to self-restrain, or hold his hand or arm so that he cannot hurt himself. PG's determination to hit himself, his surprising quickness and strength when he is determined, his aggression toward staff when he is agitated, and the unpredictability of his moods make restraint a necessity from time to time. Illness, shift changes, and exposure to

people unfamiliar to him are agitating factors for PG that contribute to the use of restraints. It is simply not possible to eliminate the need for restraints entirely.

CVTC has made a concerted effort to reduce PG's time in restraints and, in general, improve his quality of life. This includes the equipment changes and additional therapy and treatment techniques described in detail above. Use of the most successful new technique, the mat table, is on the increase. Efforts also include increased emphasis on verbal skills and going outside for field trips, both on the CVTC campus and off. The staff who works most closely with PG note progress for PG—he has begun to laugh again, his efforts to verbalize have increased, and he is being exposed to a greater variety of experiences.

The same staff notes that PG goes through cycles when he is more agitated and has a greater need to be restrained. And, new techniques "wear off" on PG so that new means of catching his interest must continuously be tried. For example, earlier this year the koosh ball was a good way to distract PG, but it no longer seems to work. Some techniques seem to work for some staff and at some hours of the day, but not others. These factors render elusive the goal of further reducing PG's time in restraints. With respect to the day shift, there is no finding of abuse, neglect, or violation of rights; Part VI contains one recommendation designed to assure that staff has the benefit of each other's expertise and experience.

The investigator's major concern is that nearly half of the time PG spends in restraints is on third shift. The situation has not been improved by measures that have proven helpful on other shifts, such as the mat table and the weighted blanket. Significantly, these measures have not been tried since the summer. As discussed above, the problem may be aggravated by the feeding schedule and also by different staffing patterns and short-staffing on third shift.

PG has the right to treatment under the least restrictive conditions feasible. This right is guaranteed by both state and federal law. Leaving PG alone in his room due to staff shortages on third shift constitutes neglect. While the investigator cannot conclude that the other aspects of PG's restraint on third shift constitute neglect, she does find that on third shift all feasible measures to reduce PG's time in restraints have not been employed. Continued failure to employ these measures would constitute neglect. In order to more fully implement PG's right to function free from bodily restraint, there are several recommendations below.

VI. RECOMMENDATIONS

A. Nose Injury

1. Meeting between facility director and everyone who was or should have been involved in the incident—nurses, the nurse practitioner, the physician KS consulted, and the social worker, to discuss what the policy is and how the required notice became "lost in the shuffle" in this particular instance.

2. Issuance of a memo by the facility director to physicians, nurses, and social workers reviewing the highlights of the notification policy, particularly where the severity

of the possible fracture or other condition is in question. If in doubt, notify. Several staff, including KS, mentioned that some family of CVTC clients do not want to be informed of anything short of a very grave injury or illness, or death. The investigator's primary concern is for interested parents such as the G's. KS stated that for her regular patients, she asks that a note be placed in the front of the record indicating that the family is particularly interested in being notified of events affecting their relative at the facility. While the applicable policies should be followed for everyone, KS' suggestion would help ensure that it is followed particularly carefully for parents such as the G's.

B. Feeding Schedule

1. As explained above, the 4:00 a.m. feeding for PG has apparently been eliminated for the time being. This will help reduce risks to PG's health due to aspiration and resulting bronchitis, pneumonia, and intestinal dysfunction. Additional recommendations are as follows:

2. Monitor PG's time in restraints on third shift to determine whether eliminating this feeding is helpful in reducing use of restraints.

3. Research available foods with higher calorie content than PG's current foods. If PG loses weight, explore with Dr. Fischer additional options to try without reinstating the 4:00 a.m. feeding—for example, different food, and/or increasing the amount of the midnight feeding.

4. Review with Dr. Fischer, Dr. P and then with staff the best protocol for elevating the bed during feeding and keeping it elevated after the feeding; staff responses on this were somewhat inconsistent, and Dr. Fischer may have additional ideas.

C. Restraints

1. "Brainstorming session" among all "front line" staff who work with PG, chaired by the nurse manager, to discuss the techniques that they find particularly useful at the present time in redirecting PG or convincing him to self-restrain. Make sure that all staff are aware that the light "tapping" PG does on his chin or cheek is considered self-stimulation and does not need to be restrained.

2. Work to eliminate staff shortages on third shift that necessitate leaving PG alone in his room while CNA's are working with other patients, thus allowing less opportunity for working with PG to redirect or self-restrain. Dr. Fischer also stated that the "one-on-one" system used for PG lessens his concern over the nighttime feedings because it allows for such careful monitoring. This staffing issue is related to feeding also.

3. Recruit a "volunteer" CNA from among the ranks to be primarily responsible for PG's care on that shift, on a trial basis. This is the type of one-on-one system recommended in the regional consultation report, and staff on other shifts believe that having one individual work primarily with PG is helpful. After a substantial trial period, perhaps six

months, have GS and JO evaluate the relevant records and interview staff to determine whether PG is spending less time in restraints.

4. Direct third-shift staff to try the mat table again. While earlier efforts were largely unsuccessful, it appears that on the most recent occasion the table was tried, it calmed PG down. If PG insists on being "up", and does not want to be on the mat table, the weighted blanket could be tried. The third shift faces unique problems with reducing use of restraints for PG, but now that the mat table is apparently being used more frequently and with success on the other shifts, it should be tried again on that shift. The same is true of any other measures that SS, other CVTC staff, or an outside consultant would recommend in order to reduce PG's time in restraints. The six-month evaluation described above should include the results of these measures as well as the one-on-one system of supervision.

5. Report to DRVD the results of implementing Recommendations 1 through 5.

6. Have an outside consultant review PG's nighttime medication schedule to determine whether valium and any other medication intended to calm PG is administered at a time when it will be the most effective in allowing him to remain calmer at night. This issue was raised by several nurses, who questioned the timing of the medications.